

“Being here is a prison”: patient-reported quality of life burdens associated with dialysis

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Introduction

Maximizing the Quality of Life (QoL) of patients is an important outcome in healthcare, along with clinical outcomes such as increasing survivorship or reducing hospital admission [1]Tavares et al, in press).

The usual assessment of QoL involves standardized questionnaires that cover diverse domains of life, namely, functionality, physical signs and symptoms, psychological and emotional aspects, and social domain. However, most QoL questionnaires restrict the patient’s choice by imposing preselected domains and items, which limits the possibility of patients to give indicate aspects that matter to them and that are a priority for their wellbeing [2](Sales et al., 2016). Moreover, QoL questionnaires have mainly been developed in younger populations, underestimating the specificity of QoL in older people with chronic disease. This is the case of end-stage renal disease (ESRD) patients undergoing dialysis, an elderly population often suffering from multiple diseases that require several treatments that may interact and interfere with patient’s QoL. Individualized Patient-Reported Outcome Measures (IPROMS) allow patients to propose freetext items that correspond to the problems that troubles them the most. Therefore, it may be a privileged way of identifying the major threats to the patients’ QoL.

In this study we aimed to listen to ESRD patients concerning what aspects of their lives are the most affected, using an IPROM.

Methods

We conducted a cross-sectional study with 97 ESRD patients (39.2% males; 69.86 ± 14.03 years old) undergoing dialysis on regular dialysis (3 times a week) in a clinical center. After informed consent, patients filled in the Psychological Outcome Profiles (PSYCHLOPS, Ashworth et al., 2004), a one-page IPROM that asks patients to indicate by their own words up to two problems that troubled them the most over the last week and a functionality issue caused by those problems. A thematic analysis of the patient-reported free-text items was conducted.

Results

The 156 free-text items revealed that the patients’ major concerns were:

Physical health symptoms (25.6%)	• “I feel tired, I do not balance very well climbing a ladder”
Family (16.0%)	• “Fear of not being healthy to take care of my children”
Autonomy (13.4%)	• “I can not go to the bathroom by myself anymore”
Domestic tasks (12.2%)	• “I can not handle the house anymore”
Treatment (9.6%)	• “Being here is a prison”
Work (7.7%)	• “Not working during dialysis (not having my laptop)”
Loneliness & Death (5.2%)	• “Staying home alone”
Other	• “I get bald” [due to chemotherapy]

Discussion

ESDR patients undergoing dialysis see their wellbeing affected by a broad range of non-clinical factors. Survival is one of the less indicated issues comparing with other domains. These results reinforce care guidelines that recommend that treatment programs should attend not only survivorship or biological outcomes but also psychosocial adjustment [3].

Managing the negative impacts of disease and treatment within the family is one of the most important priorities of ESDR patients.

Conclusion

The familial domain should be considered as a priority care domain of ESDR patients, in order to enhance QoL.

References

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